#### **Basics**



## What is it?

# Points To Remember About Systemic Lupus Erythematosus (Lupus)

- Lupus can affect many body parts, including the joints, skin, kidneys, heart, lungs, blood vessels, or brain.
- You will have periods of illness (flares) and wellness.
- Anyone can get lupus, but it most often affects women. Lupus is also more common among African American, Hispanic, Asian, and Native American women.
- Genes play an important role in lupus, but other factors are also involved.
- Most people will see a rheumatologist for their lupus treatment. Treatment generally consists of a team approach.
- Learning to recognize the warning signs of a flare can help with reducing or preventing the flares.

Systemic lupus erythematosus (lupus) happens when the body's defense system attacks healthy cells and tissues, instead of viruses and bacteria. This can damage many parts of the body such as the:

- Joints.
- Skin.
- Kidneys.
- Heart.
- Lungs.
- · Blood vessels.
- Brain.

You can't catch lupus from another person. If you have lupus you will have periods of illness (flares) and wellness.

## Who gets it?

Anyone can get systemic lupus erythematosus (lupus), but it most often affects women. Lupus is also more common in African American, Hispanic, Asian, and Native American women than in Caucasian women.

# What are the symptoms?

Symptoms of lupus vary, and they may come and go. The times when a person is having symptoms are called flares, which can range from mild to severe. New symptoms may appear at any time.

Some of the most common symptoms of lupus are:

- Pain or swelling in the joints.
- · Muscle pain.
- Fever with no known cause.
- Red rashes, most often on the face.
- Chest pain when taking a deep breath.
- Hair loss.
- Pale or purple fingers or toes.
- Sensitivity to the sun.
- Swelling in the legs or around the eyes.
- Mouth sores.
- Swollen glands.
- Feeling very tired.

Less common symptoms include:

- Anemia (a decrease in red blood cells).
- Headaches.
- Dizzy spells.
- · Feeling sad.
- Confusion.
- Seizures.

### What causes it?

No one knows what causes systemic lupus erythematosus (lupus). Research suggests that genes play an important role, but genes alone do not determine who gets lupus. It is likely that many factors trigger the disease.

## Is there a test for it?

There is no single test to diagnose systemic lupus erythematosus (lupus). It may take months or years for your doctor to diagnose the disease. Your doctor may use many tools to make a diagnosis:

- Medical history.
- Complete physical exam.
- Samples from the blood, skin, or kidneys for laboratory tests.

## How is it treated?

Your doctor will develop a treatment plan to fit your needs. You and your doctor should review the plan often to be sure it's working. You should report new symptoms to your doctor right away so that treatment can be changed if needed.

Treatments may include:

- Medicines to:
  - Reduce swelling and pain.
  - Prevent or reduce flares.
  - Help the immune system.
  - Reduce or prevent damage to joints.
  - Balance the hormones.
  - Treat problems related to lupus, such as high cholesterol, high blood pressure, or

infection.

 Alternative treatments may improve symptoms. No research shows that this kind of treatment works for people with lupus. You should talk to your doctor about alternative treatments.

## Who treats it?

Most people will see a rheumatologist for their systemic lupus erythematosus (lupus) treatment. Treatment generally consists of a team approach and may include:

- Family doctors, who can work with your other doctors to coordinate your care.
- Clinical immunologists, who treat problems with the immune system.
- Nephrologists, who treat kidney disease.
- Hematologists, who treat blood disorders.
- Dermatologists, who treat skin problems.
- Neurologists, who treat problems of the brain and spinal cord.
- Cardiologists, who treat problems with your heart and blood vessels.
- Endocrinologists, who treat problems related to the glands and hormones.
- Nurses.
- · Psychologists.
- · Social workers.

# **Living With It**

Dealing with a long-lasting disease like systemic lupus erythematosus (lupus) can be hard on the emotions. You might think that your friends, family, and coworkers do not understand how you feel. Sadness and anger are common reactions.

Besides working with your doctor to determine a treatment plan, there are a few things you can do to help you live with lupus:

- Learn to recognize the warning signs of a flare so that you and your doctor might reduce or prevent them. These warning signs include:
  - Feeling more tired.
  - o Pain.
  - o Rash.
  - o Fever.
  - Stomachache.
  - Headache.
  - Dizziness.
- Eat a proper diet, exercise, and learn relaxation techniques to help cope with stress. A
  healthy lifestyle, as well as quitting smoking, will also reduce your risk for heart disease
  associated with lupus. Talk to your doctor before starting an exercise program.

• Develop and maintain a good support system of family, friends, medical professionals, community organizations, and support groups.

## **Pregnancy and Contraception for Women With Lupus**

Pregnancy in women with lupus is considered high risk, but most women with lupus carry their babies safely. There are a few things to keep in mind:

- Talk to your doctor if you plan to become pregnant.
- See your doctor often once you are pregnant.
- Good nutrition during pregnancy is important.
- Lupus can flare during pregnancy.

Recent studies have shown that birth control pills are safe for women with lupus.

## For More Info

## **U.S. Food and Drug Administration**

Toll free: 888-INFO-FDA (888-463-6332)

Website: https://www.fda.gov

<u>Drugs@FDA</u> at <a href="https://www.accessdata.fda.gov/scripts/cder/daf">https://www.accessdata.fda.gov/scripts/cder/daf</a> <a href="mailto:Drugs@FDA">Drugs@FDA</a> is a searchable catalog of FDA-approved drug products.

#### Centers for Disease Control and Prevention, National Center for Health Statistics

Website: https://www.cdc.gov/nchs

# American College of Rheumatology

Website: <a href="https://www.rheumatology.org">https://www.rheumatology.org</a>

## Alliance for Lupus Research, Inc.

Website: https://www.lupusresearch.org

#### American Autoimmune Related Diseases Association, Inc.

Website: https://www.aarda.org

#### **Arthritis Foundation**

Website: https://www.arthritis.org

#### **Lupus Clinical Trials Consortium, Inc.**

Website: https://www.lupusclinicaltrials.org

## **Lupus Foundation of America**

Website: https://www.lupus.org

#### **Lupus Research Institute**

Website: https://www.lupusresearchinstitute.org

#### **SLE Lupus Foundation**

Website: https://www.lupusny.org

If you need more information about available resources in your language or other languages, please visit our webpages below or contact the NIAMS Information Clearinghouse at NIAMSInfo@mail.nih.gov.

- Asian Language Health Information
- Spanish Language Health Information

#### Join a Clinical Trial

Find a Clinical Trial

#### **Related Information**

Lupus, Lo que las personas con lupus deben saber sobre la osteoporosis Cómo vivir con lupus: Información básica de salud para usted y su familia

#### View/Download/Order Publications

Lupus, Easy-to-Read Fast Facts

Lupus, Living With: Health Information Basics for You and Your Family Lupus, What People With Lupus Need to Know About Osteoporosis Systemic Lupus Erythematosus, Handout on Health